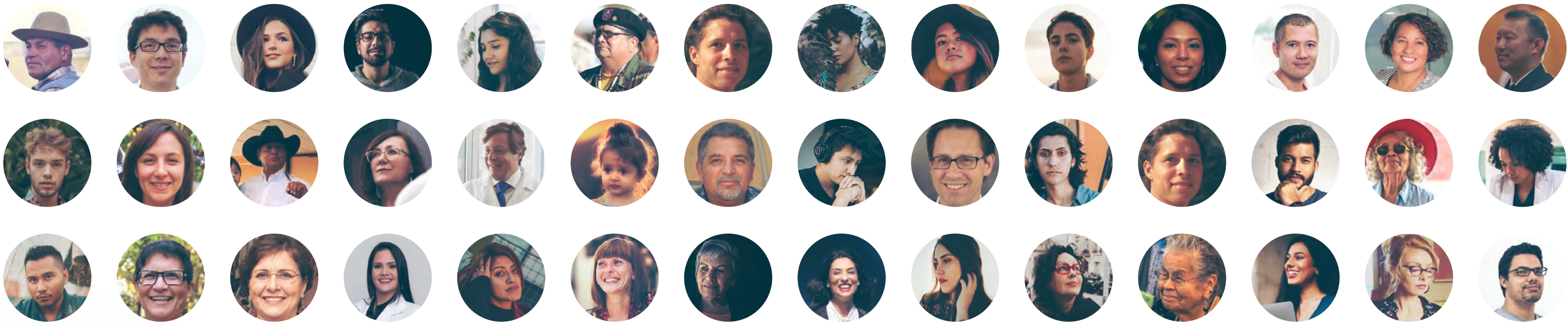
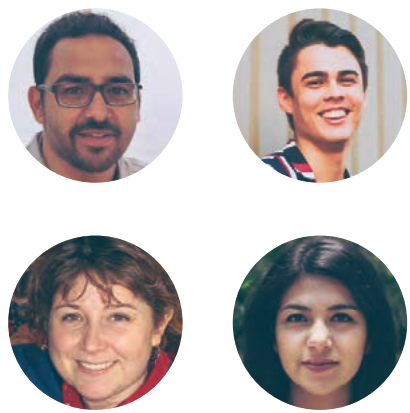


INDIAN HEALTH SERVICE HUMAN-CENTERED DESIGN

JOURNEY 7: CARING FOR A LOVED ONE [SECTION 9 OF 11]



SERVICE BLUEPRINTS

How to read the Service Blueprints

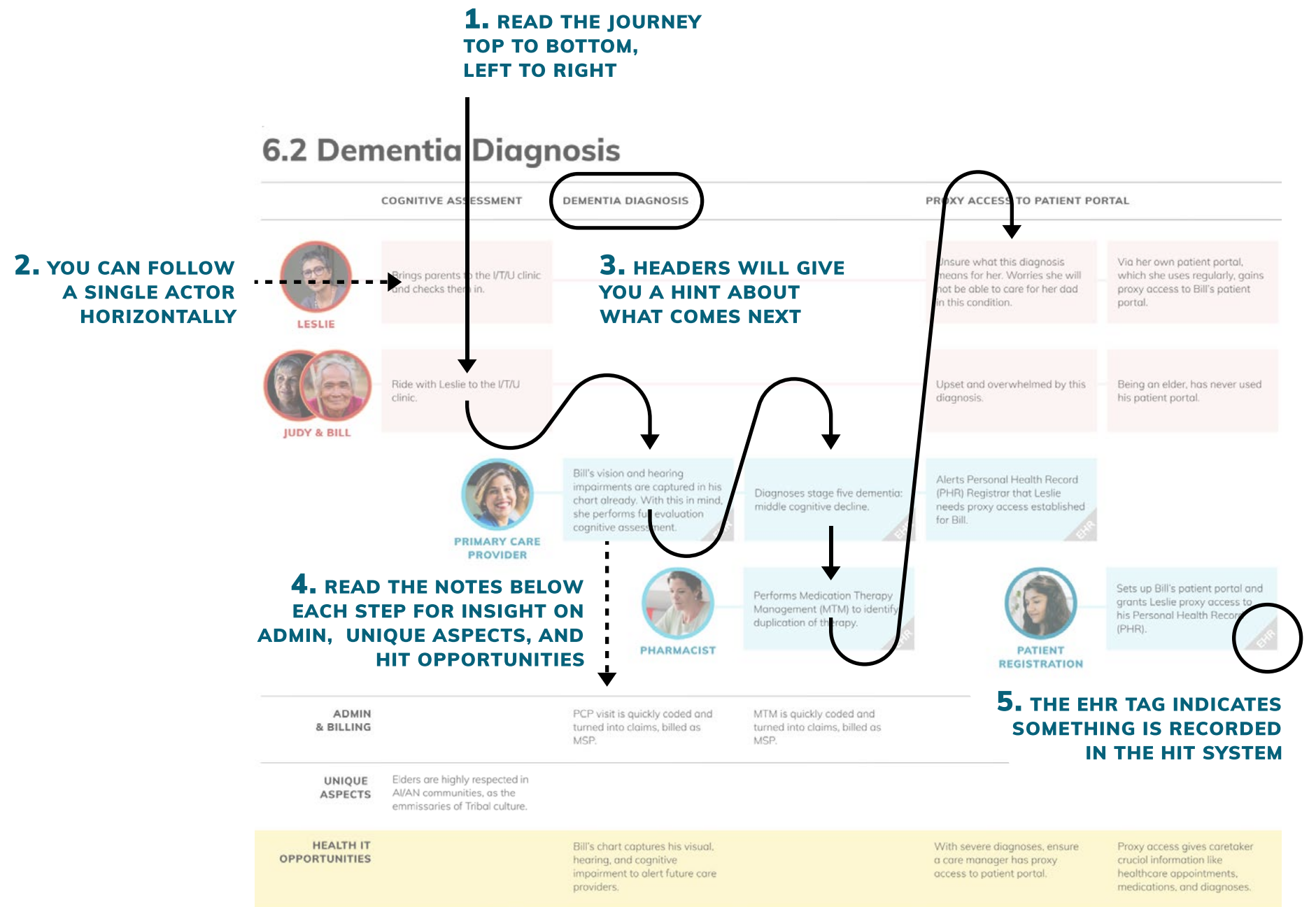
The journeys in this report present seven stories of patients and caretakers receiving care in adverse circumstances. The purpose is to convey stories that, read collectively, paint a dynamic and encompassing picture of the varying needs of the AI/AN population and IHS staff when it comes to health services.

These are composite experiences of real people and the processes they engage in to seek and provide care. Examples of regulations and reporting requirements are pulled from interviews and Subject Matter Experts.

However, these represent a “happy path” from an IT perspective. While retaining real challenges in the landscape such as ruralness and lack of connectivity, IT solutions are added to the stories to illustrate how IHS might service existing needs with modern solutions. These solutions are not meant to be prescriptive. They are simply examples of how Health IT can improve care. Solution-agnostic use cases are listed at the end of this report.

How the Stories Were Crafted

The HCD team selected stories based on patient’s health disparities for AI/AN patients. The sequence of events was crafted to highlight Health IT opportunities and unique aspects of I/T/U that can be affected positively by Health IT opportunities as comprehensively as possible. Many health disparities and health outcomes were left out due to scope and to whether it covered a variety of Health IT opportunities. Workshops with team members from the Health IT Modernization project, HHS and the IHS were conducted to ensure the right opportunities were being highlighted based on experience and discovery conducted by many of those team members.



JOURNEY 7: CARING FOR A LOVED ONE

LESLIE'S JOURNEY

Leslie's father, Bill, suffers a decline in health. Leslie and her mother, Judy, become more involved in his healthcare. They have support from the local healthcare facility and home care.

ELDERS

HOME CARE

MEDICARE

TELEHEALTH

END OF LIFE CARE

EMERGENCY DEPARTMENT

REMOTE MONITORING

IHS FACILITY

DEMENTIA

Leslie and Her Parents' Background

Leslie lives a short drive from her parents, Bill and Judy. She is a full-time elementary school aide on the reservation.

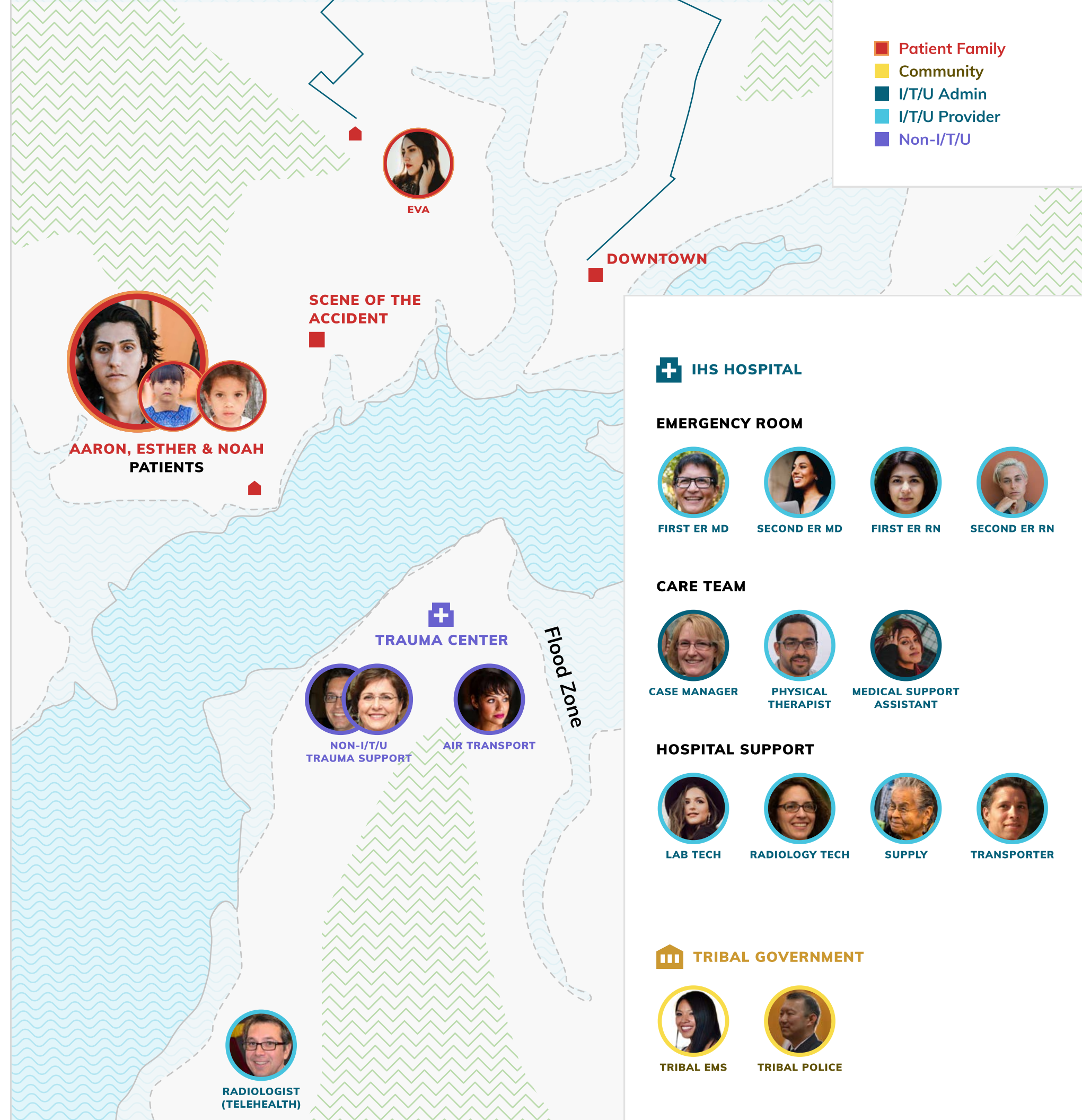
As the oldest child, she takes the bulk of the responsibility of helping her parents. They live near a town on the edge of the reservation. Bill and Judy and speak their native tongue in the home and enjoy eating traditional foods when they can.

Bill loves his home; however, it is not an "easy" home. There are steps to the entryway and a narrow space by his bed.

Bill spent many years attending Tribal meetings, and being very involved in the community. Recently, Bill does not seem to want to attend Tribal meetings. He has been dropping and forgetting things more than usual.

Bill's vision and hearing are pretty impaired, so it is hard to tell how much he understands. Judy has raised concerns about his memory and cognition.

Bill and Judy are enrolled in Medicare and Medicaid, so they have Medicaid as a Secondary Payer (MSP). They have been seeing the same Primary Care Physician for over a decade.



7.1 Bill's Cognitive Decline

LESLIE HELPS HER PARENTS

BILL STAYS IN

ARRANGES A DOCTOR'S VISIT



LESLIE

Works weekdays at the local elementary school. Visits her parents several times a week, often bringing dinner.



BILL

Indicates to Judy that he would like to skip the Tribal meeting this week—for the third time in a row.



JUDY

Worried, calls Leslie to complain that Bill will not leave the house.



SCHEDULING

Sets up a doctor's visit for the following week.

Finds a time for him to come in the following week.

ADMIN & BILLING

UNIQUE ASPECTS

Elders are highly respected in AI/AN communities, as the emissaries of Tribal culture.

Family members are often tasked with managing the care of less autonomous patients.

HEALTH IT OPPORTUNITIES

7.2 Dementia Diagnosis

COGNITIVE ASSESSMENT

DEMENTIA DIAGNOSIS

PROXY ACCESS TO PATIENT PORTAL



LESLIE

Brings parents to the I/T/U clinic and checks them in.



JUDY & BILL

Ride with Leslie to the I/T/U clinic.



PRIMARY CARE PROVIDER

Bill's vision and hearing impairments are captured in his chart already. With this in mind, she performs full evaluation cognitive assessment.

EHR

Diagnoses stage five dementia: middle cognitive decline.

EHR

Alerts Personal Health Record (PHR) Registrar that Leslie needs proxy access established for Bill.

EHR



PHARMACIST

Performs Medication Therapy Management (MTM) to identify duplication of therapy.

EHR



PATIENT REGISTRATION

Sets up Bill's patient portal and grants Leslie proxy access to his Personal Health Record (PHR).

EHR

Unsure what this diagnosis means for her. Worries she will not be able to care for her dad in this condition.

Via her own patient portal, which she uses regularly, gains proxy access to Bill's patient portal.

Upset and overwhelmed by this diagnosis.

Being an elder, has never used his patient portal.

ADMIN & BILLING

PCP visit is quickly coded and turned into claims, billed as MSP.

MTM is quickly coded and turned into claims, billed as MSP.

UNIQUE ASPECTS

HEALTH IT OPPORTUNITIES

Patient chart includes visual, hearing, and cognitive impairment to alert future care providers. Also includes social determinants of health.

With severe diagnoses, ensure a care manager has proxy access to patient portal.

Proxy access gives caretaker crucial information like healthcare appointments, medications, and diagnoses.

7.2 Dementia Diagnosis (cont'd)

POWER OF ATTORNEY

PATIENT PORTAL BY PROXY



LESLIE

Discusses the need for Power of Attorney with her parents.

Immediately able to see Bill's diagnosis, plan of care, and helpful information in his patient portal via proxy access

EHR



PRIMARY CARE PROVIDER

Recommends that Leslie obtain Power of Attorney.



PATIENT REGISTRATION

Offers translation services to Bill and Judy. Brings in two witnesses, and herself a notary, grants Power of Attorney that day.

With documentation, notes this in the EHR.

EHR

EHR



JUDY & BILL

Understands and agrees that Leslie should have Power of Attorney. Signs over Power of Attorney with a notary.

ADMIN & BILLING

UNIQUE ASPECTS

With severe diagnoses, ensure a care manager has proxy access to patient portal.

Having a notary on staff at a clinic saves patients time for legal matters like POA.

HEALTH IT OPPORTUNITIES

Power of Attorney information on EHR

Patient portal can also provide education and links to community resources.

7.3 Bill Goes to the ER

FALLS ON A WALK

GOES TO ER



LESLIE

Knowing Bill's condition, visits more frequently, but able to continue working and keep a regular schedule.

Drives as fast as she can to her parent's house, and takes them to the Emergency Room.



BILL

Goes on walks with Judy to get out of the house without the burden of conversation. Enjoys communing with nature.

Returning from a walk with Judy, falls at the front steps of their house.

Gives emergency key fob to ER team, providing access to his medical record, and lets them know who to inform of his new injury.

Extremely disoriented, cannot self advocate, cannot use a walker.

Given an IV with antibiotics for his UTI because he is unsure of his ability to take oral antibiotics.



JUDY

Takes Bill on walks, which is a cherished way for them to spend time together with his declining cognitive state.

Calls Leslie and checks to make sure Bill's emergency key fob, which contains his medical record, is on their key chain.



NON-ITU ER

Sees that Bill has dementia as well as hearing and visual impairments, and sees that Leslie has POA. This informs his diagnosis and treatment.

Diagnosis Bill with a sprained ankle, and incidentally finds that he has a UTI comorbidity.

ADMIN & BILLING

ER facility will bill Medicare and Medicaid for visit and treatment.

UNIQUE ASPECTS

Married elders are often together, and rarely apart.

In times of need, the nearest ER is the best option, regardless of whether it is I/T/U.

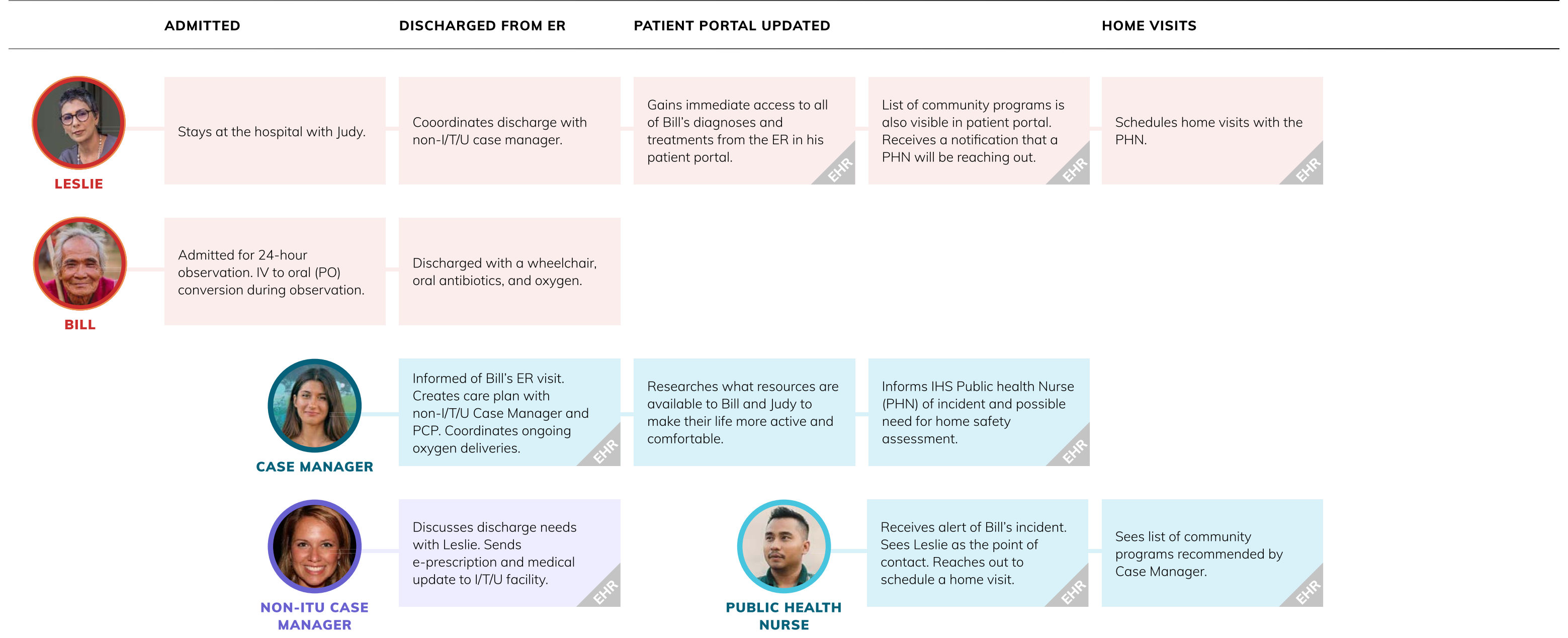
UTIs are not uncommon among elder patients who cannot speak for themselves.

HEALTH IT OPPORTUNITIES

A device with the patient's medical record removes the burden of verbally communicating their history.

It is valuable for the patient to see all Medicare claims from various facilities in one place.

7.3 Bill Goes to the ER (cont'd)



ADMIN & BILLING

With doctor's order, these items are covered by Medicare and Medicaid.

UNIQUE ASPECTS

PHNs can visit patients at home if they are not able to come into the clinic regularly.

HEALTH IT OPPORTUNITIES

Able to receive e-prescriptions from ER as well as update medical chart at the time of the encounter.

Access to a loved one's patient portal enables care managers to stay organized.

Patient portals can also be a location to share community resources.

7.4 Home Modifications

ORDERS HOME MODIFICATIONS

COMMUNITY SUPPORT



LESLIE

Goes to her parents house for the PHN visit, so she can speak with him and manage next steps.

Oversees installation of modifications at her parent's home.

Worries she will have to work part time instead of full time to continue supporting her dad.

Arranges Meals on Wheels and other programs to visit Bill and Judy when she cannot be around.



PUBLIC HEALTH NURSE

Visits Bill's home. Fills his pill box, performs Fall Risk Mitigation, assesses other needs, and informs PCP.

Brings supplies such as underpads for Bill's bed and wheelchair in case he cannot make it to the bathroom at night.

Trains Leslie and Judy to help Bill move from his bed to his wheelchair.

Informs Leslie of programs available to bring community support to Bill when she cannot be around.



JUDY

With the wheelchair ramp, can take Bill for walks in his wheelchair, so he can continue enjoying nature.



PRIMARY CARE PROVIDER

Orders electric hospital bed, transfer bench, grab bar, and ramp for Fall Risk Mitigation.



BILL

Can now move around the house more independently. Enjoys visits from family and community members.



MEALS ON WHEELS

Visits Bill with food and stays for conversation.

ADMIN & BILLING

Home improvements are quickly coded and turned into claims, billed as MSP.

PHN visit and supplies are quickly coded and turned into claims, billed as MSP.

In-home trainings can be recorded for quality measures.

UNIQUE ASPECTS

Access to nature is valued, and beneficial to spiritual and mental health.

Care providers can inform patients and family of programs available to them, to lighten the load.

HEALTH IT OPPORTUNITIES

EHR records home details and can track activities of daily living such as eating, bathing, and toileting.

Mobile, asynchronous access to EHR allows the PHN to update information and request home modifications in real time.

7.5 Condition Worsens

FURTHER COGNITIVE DECLINE

PLANS TO VISIT PCP



LESLIE

Visits Judy and Bill more frequently, as Bill's condition worsens over time. Worries about leaving them alone.

Wants to take Bill to the doctor, but does not know how to get him there. Cannot get him into the car in his condition.



BILL

Does not seem to know what to do with utensils. Stops feeding himself.

Stops using comprehensible words.



JUDY

Unable to lift or move Bill without significant teamwork from Leslie. He is starting to fight her during these moments.

Begins feeding Bill, but it is a difficult, time-consuming process. Not to mention, emotionally taxing.



PUBLIC HEALTH NURSE

On home visits, performs regular mini mental exams to track Bill's cognitive performance. Enters score in the EHR.

Continues to document activities of daily living. Sees that care has become impossible. It is clear that Bill's health is declining.

Notifies Case Manager, schedules appointment with PCP, arranges transportation to the Tribal clinic.

ADMIN & BILLING

PHN visit is quickly coded and turned into claims, billed as MSP.

UNIQUE ASPECTS

Oftentimes, when patients do not know how to access care, they do not access care.

HEALTH IT OPPORTUNITIES

EHR can graphically track cognitive score over time.

PHN can quickly alert the care team and arrange transportation while with the patient.

7.6 Hospice Evaluation

TRANSPORT TO CLINIC

SELECTS HOSPICE PROVIDER



JUDY & LESLIE

Judy and Leslie follow the ambulance to Tribal clinic. Thankful that EMTs were able to transport him.

Speak for Bill during PCP encounter.

Select a Hospice program and a time for assessment.

EHR



BILL

Attends PCP encounter visit passively.



PRIMARY CARE PROVIDER

Determines Hospice to be appropriate and notifies Case Manager.

EHR



CASE MANAGER

Recommends a few Hospice programs.

EHR

Discusses with family and coordinates initial visit by Hospice provider.

EHR

Shares Bill's medical information with Hospice provider, and arranges assessment.

EHR

ADMIN & BILLING

Ambulance transport is quickly coded and turned into claims, billed as MSP.

UNIQUE ASPECTS

Sometimes, there is a Tribal EMS, other times I/T/U facilities must outsource EMS services.

Hospice programs near reservations are more likely to know about traditional culture and eating habits.

HEALTH IT OPPORTUNITIES

Can easily obtain patient's permission via proxy and send relevant medical information to the Hospice provider.

7.7 Hospice

HOSPICE EVALUATION



LESLIE

Meets Hospice nurse at Bill and Judy's house.

Required to track several different Hospice Aides and report their hours.

Informs family that Bill is on Hospice. Encourages them to visit.

Reaches out to the Tribal funeral home and initiates burial plans.



HOSPICE NURSE

Assesses Bill for Hospice. Finds that he meets criteria for admission, and sets up Hospice care at home.

Determines that family needs 24-hour care for Bill, which is covered by Medicaid.

Explains Hospice care and helps prepare the family for end of life process.



PHARMACIST

Alerted of Hospice admission, discontinues all chronic medication.



CASE MANAGER

End of life plan is saved in EHR.



HOSPICE AIDE

Begin visiting Bill right away. Aides bathe and feed Bill, and support the family.

Worker schedule is consistent and clear, so as not to disorient Judy, and to make Leslie's life easier.

ADMIN & BILLING

Hospice bills Medicare then Medicaid, directly.

UNIQUE ASPECTS

Tribal funeral homes use traditional burial practices.

HEALTH IT OPPORTUNITIES

Information about Hospice admission is transmitted to patient's chart.

Resources and next steps are available on patient portal.

Patient's end of life plan is documented in the chart.

7.8 Bill's End of Life

BILL PASSES AWAY

FUNERAL



JUDY & LESLIE

Find Bill one morning, not breathing.

Notify family and community of Bill's death.

Notify PCP of Bill's death.

Celebrate Bill's life with family and per his wishes.



BILL

Dies in his sleep. He is with his family. Clean, dignified, and as comfortable as possible.



TRIBAL FUNERAL HOME

Picks up Bill's remains. Issues certificate of death. Hosts funeral for Bill.



HOSPICE AIDE

Call Hospice Nurse



HOSPICE NURSE

Drives to Bill's home. Does paperwork. Calls Tribal funeral home to pick up Bill's remains.

ADMIN & BILLING

Patient's chart must remain open until all claims are processed.

UNIQUE ASPECTS

Quietly and respectfully documenting patient's death allows the family to focus on grieving.

Funeral home handles all arrangements.

HEALTH IT OPPORTUNITIES

Patient's death is documented in EHR, and the chart is closed after all claims are complete.

HHS / IHS Health IT Modernization

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